

Mack Welch Joins ASCC Case Management Staff

Mack Welch joined the Arkansas Spinal Cord Commission staff in July, replacing Bernie Quell who was promoted to Intake Coordinator. Mack has assumed the responsibilities of Case Manager for parts of Pulaski and Saline Counties. He is a graduate of the University of Arkansas with a Master's degree in Rehabilitation Counseling.

Mack has twenty-one years experience in both private and public sectors of vocational rehabilitation. He has had extensive experience and training in the ADA and, fortunately for ASCC, also has an excel-

lent background in mechanics and woodworking. His diverse career has enabled him to work with individuals with many different disabilities including individuals with spinal cord disabilities.

Mack and his wife Laura Lee, who is also a health care professional, are residents of Little Rock. They have one daughter, Mallorie age nine.

The Commission members and staff of ASCC are fortunate to have such a qualified individual joining our agency. Mack is looking for-



Mack Welch is the new ASCC Case Manager in the Little Rock office.

ward to meeting and serving the individuals on his caseload. Please join us in welcoming Mack!

Passages Program

Passages is an exciting new program designed to serve Medicaid residents in nursing homes. This program seeks to help individuals who wish to return to their own home or who desire a more familiar living arrangement. Nursing home residents who meet the following criteria are eligible for the *Passages* Program:

- Age 21 or older
- Currently receiving Medicaid
- Want to move back home
- Have needs that can be successfully met by existing programs

Each individual who is referred and meets the above criteria receives an assessment and a detailed transition plan for returning home. Support services will pay for items or services to ensure that the partici-

pant's environment promotes quality of life and independence. Services may include:

- Temporary rent
- Utility deposits
- Home modifications
- Furniture
- Non-medical transportation
- Attendant care
- Personal care
- Companion services
- Home health
- Other in-home services
- Other necessary items not available from other funding sources

Application for the *Passages* Program may be made by contacting the Division of Aging and Adult Services at the toll-free number **1-888-682-0044**.

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SPINAL COURIER

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With Thanks

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Lois Pfeiffer

In Memory of Keith Lewis
John and Carolyn Haisty
Marvin and Sandra Green
Mr. and Mrs. William Walker
Jerry and Elizabeth Dickson

ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Woodworking Anyone?

Dear Editor:

I am a very active person with a spinal cord injury who is interested in woodworking. I live in the Conway area and would like to get together with other individuals who are interested in wood-

working. I have access to tools and wood. If anyone is interested in starting a woodworking group, I can be contacted at **501-450-7354**.

Sam Fitzgerald
Conway, AR

From the Director

By the time you read this, we will be in the middle of autumn, my favorite season. But right now, it's the dog days of summer, and I'm wondering how over half the year has passed us by already! A few musings on summer 2001:

- I became ambidextrous this summer, broke my left arm the first week in June and spent June and July writing and typing with the "wrong" hand. I'm not sure who had more trouble—me writing or everyone else trying to read what I'd written. Okay, so maybe I'm not ambidextrous.
- The orange traffic safety barrel should become the state animal. As I traveled the state this summer setting up our regional loan closets, I spent many hours playing "chicken" with the orange plastic barrels on roads and highways. I didn't count, but I'm sure there are more barrels than dogs in Arkansas this summer!
- Camp Aldersgate has got to be one of the greatest places in Arkansas, with acres of beautiful grounds, a lake, a pool, pretty good food, wonderful staff—heaven on earth for kids. So why are we not getting campers for Spina Bifida Camp? There's no cost to families, and we can take up to 50 campers ages 6 to 16 for the week. Last year we had 43, this year only 32 campers! What can we do to get kids to come?
- I'm a bit of a political junkie, read all the reports I can find about what goes on in Congress (okay, so I'm easily entertained). I read about a piece of legislation this week that caused me to sit up and yell! Sen. Barney Frank has (finally) submitted Social Security Disability legislation that would do away with the five month waiting period and the two year waiting period for Medicare eligibility! If you received SSDI, you remember those ridiculous waits! It's a bill that makes too much sense to pass. But keep your fingers crossed! MICASSA, the legislation to promote more community-based personal assistance options, is also gaining steam again.

• Mark Hoyt's article about separate handicapped and wheelchair parking in our July issue has stirred some interest—it will be published in *Paraplegia News* next month!

Enjoy the Fall and the holidays!

Cheryl Vines

If you would like to make a contribution, please contact the Commission at **501-296-1788/800-459-1517** (voice)/**501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207

Project A-WIN

What do you do if you get Social Security Disability or Supplemental Security Income benefits because of a disability and you would like to try working again, but are afraid of losing your health benefits under Medicare or Medicaid? According to Bill Knight, Executive Director of Project Arkansas Work Incentives (A-WIN) in Fayetteville, this is the quandary many people with disabilities face.

“Social Security law has always included ‘incentives’ for people to attempt reentry into the work force,” says Knight. “However, due to their complexity, these have often served as unintentional barriers to work. Social Security says that less than one-half of one percent of disabled beneficiaries ever return to full time work at a salary that provides self-sufficiency. This is despite surveys that show most people would prefer to work. The problem has been alleviating their fears that an unsuccessful work attempt would cost them their disability benefits while still leaving them without a job.”

Congress addressed this problem with the Ticket to Work and Work Incentives Improvement Act of

1999. This law greatly expands the opportunities for someone to test his ability to work, without immediately jeopardizing his benefits.

“This is what created Project A-WIN and similar programs in other states,” says Knight. “The Social Security Administration made grants to cover 95% of the costs of providing information, counseling and benefits planning assistance to disabled individuals. In Arkansas, we have four benefits specialists who are skilled in applying the many Social Security work incentives to an individual’s personal situation, and helping them develop a plan to protect their benefits until they become established again in a job or business of their own.”

For more information, call toll-free statewide **888-284-7521**. Or you may contact Benefits Specialists:

- Randy Alexander in Pine Bluff at **870-535-2222**
- Karen Swinton in Little Rock at **501-280-0012**
- Jerry Clawson in Fayetteville at **501-442-5600**
- Michelle McCoy in Hot Springs at **501-624-7710**.

All Project A-AWIN services are free of charge.

Hats Off to DeGray Lodge!

By Jim Debruin, El Dorado, AR

I have not stayed at all of the state parks, but have been to Lake Chicot, Lake Catherine and Lake Ouachita. All of these are okay, with the exception of Lake Ouachita where there is no roll-in shower. In the spring of this year I was at Hot Springs and on the way home I stopped at DeGray Lodge at DeGray Lake Resort State Park close to Arkadelphia. To my pleasant surprise, they finally got it right!

I think the Lodge’s rooms on the lakeside had full-size beds and the

ones on the back side had king-size beds. Every person has things that impress them. What really got me was the pool and hot tub—they have lifts! In addition, the Lodge has a really nice wheelchair accessible walkway that winds down by the lake. The pool was not open when we stopped by, but is probably open during the summer. Also, they have a good restaurant.

My hat goes off to all the people who helped design and build this facility. I look forward to visiting there again!

Spina Bifida Camp 2001

For the thirty-two young campers with spinal cord disabilities who spent a week at Spina Bifida camp the last week in June, Camp Aldersgate is a special place. Besides being a very accessible and modern camp, the activities this summer provided a challenge for everyone.



Campers joined either the Caddo or Quapaw tribes Sunday and members of the tribes competed to earn points all during the week. Activities included fishing, canoeing, hand powered boating, a ropes course (pull themselves up and ride the zip line down), music and crafts. The excitement built all week until the awards ceremony Friday morning.

With many family members and staff present, each camper received an award. Heather Bowers of Hensley was awarded the Joe Morgan SuperCamper award. At last it was time—the beads were totaled and the Caddo tribe was victorious this year, by the narrow margin of 415 to 400 points!

Spina Bifida Camp is a collaborative program supported by the Arkansas Spinal Cord Commission, Camp Aldersgate and MedCamps of Arkansas.



Aging with a Spinal Cord Injury

By Tom Kiser, M.D., ASCC Medical Director

I recently attended a conference on aging with spinal cord injury (SCI) given by the Rancho Los Amigos National Rehabilitation Center. I want to share with you some the information I obtained from the conference.

In 1940, the average life span of a person with SCI was 26 years of age, while the life span of the general public was 58 years. In 2000, the average life span for SCI is 65 years of age and the general public is 78 years. This was a 30% increase for the general public, but a 150% increase for SCI. With a longer expected life span you will have to prepare for age-related changes as you get older. Getting older is not easy for any of us, but if you have a spinal cord injury it is even more difficult.

Improvements in muscular endurance and strength peak at about 20 years of age. Mentally and socially, we are functioning at our peak at around forty or fifty years of age. These are general numbers and ages for the general population, but are important, because we all have to deal with aging and functional decline. The functional decline from these peaks on average is about 1% per year for the general population and about 1.5% per year for individuals with a SCI. There are many possible explanations for the increased rate of decline for individuals with SCI, such as:

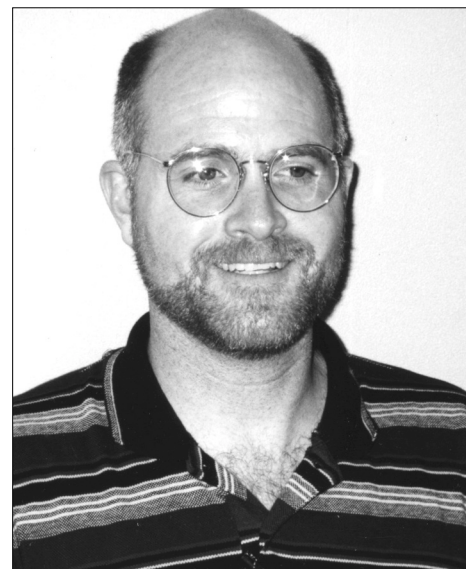
1. Multiple secondary medical conditions (UTI's, pressure sores, chronic constipation, osteoporosis, increased incidence of heart disease, etc.).
2. Altered cellular aging in SCI.
3. Age at the time SCI (older age

is worse) occurred.

4. Era or decade (1950's, 1960's, etc.) in which your injury occurred (heavier wheelchairs, decreased efficacy of medications, etc.).
5. Duration of time since your injury (wear and tear on upper extremities and body).
6. The ability to cope with problems as we age.

What can you do to age gracefully, prevent problems and manage the unavoidable decline in function?

1. A routine aerobic exercise program to improve endurance and increase HDL (the good cholesterol) is helpful, but you must use good exercise technique to protect the shoulders (hand cycles, wheelchair activity and swimming are a few suggestions).
2. Stop smoking if you do smoke, and do not start if you do not smoke.
3. Eat a healthy and nutritious diet.
4. Get a yearly flu vaccination and a pneumococcal vaccination at least one in your life time (some health professionals recommend every ten years). Pneumonia is the number one killer in SCI.
5. Avoid pressure sores, by doing your pressure relief, sitting on a good cushion and checking your skin every day.
6. Get a yearly medical and functional evaluation. This will
7. Prioritize your activities and goals. You need a long-term perspective. Spend time assessing where you are and where you want to go. Pace yourself and make incremental changes in your life to attain your goals.
8. Build and maintain a good social support system. Take good care of your family and friends. They need you and you need them.



allow your physician and a physical or occupational therapist to address any problems you are having. **Do not accept functional decline just because you are aging.** There are many medical problems that can develop (carpal tunnel syndrome, syringomyelia, poor posture, and a pinched nerve—to name a few) that can be treated. Technological advancements in equipment and treatment and improvement in medication are other reasons to stay in touch with your physician and therapist.

As life expectancy increases, it is necessary to make adjustments to cope with age-related changes. Aging with SCI need not be as problematic as many fear if appropriate steps are taken to maintain good health and function.

What You Should Know about CAPPS, Part II

The Consumer Action to Prevent Pressure Sores (CAPPS) project was a research study conducted by the Arkansas Spinal Cord Commission and funded by the Centers for Disease Control and Prevention. In Part I of this article we talked about how the intervention group had reduced the number and severity of their pressure sores while the control group did not. We concluded that the in-home education intervention was successful and asked you to review your measures for preventing sores.

Here in Part II, we look at some of the general characteristics of the whole group of 66 project participants. As you may remember, the participants were all persons with spinal cord injury, aged 18 to 65, but the general conclusions could apply to all persons with spinal cord disability.

Demographics

The group consisted mostly of males (80.3%) and slightly more blacks (51.5%) than whites. The ages of the participants ranged from 20 to 65, with an average age of 40.4 years. A high school diploma was the highest educational level attained for one-fourth (27.3%) of the group, but 71.2 percent had at least a high school diploma or more. The number of years post-injury ranged from 2 to 39 with an average of 12.6 years. The neurological level of most of the participants was paraplegic (59.1%) and most of them used a manual self-propelled wheelchair. The average 1997 household income for all participants was \$11,426.

Pressure Sore History

Nearly three-fourths (72.7%) of the group reported having a sore since their spinal cord injury, and of these 48 participants 43.8 percent had been hospitalized for treatment of the sore. Upon entrance into the CAPPS study, 20 participants re-

ported having a pressure sore, 28 (42.4%) said they had a sore in the past but not now and 18 (2.3%) said they had never had a sore. However, after examination by a physician, six participants who reported not having any sores were found to have a sore. When asked how concerned they were about developing a pressure sore, 28.8% were not concerned, 36.4% were slightly or moderately concerned, and 34.7% were very concerned.

Smoking

A high percentage (45.5%) of participants in this study smoked. Although smoking and the presence of sores were not statistically related in this study, smoking compounds the effect of pressure on the cell tissues. Pressure reduces blood vessel size thus reducing blood flow and smoking reduces the amount of oxygen that can be carried by the blood.



Alcohol

Although 43.9 percent of the participants did not consume alcohol, 25.8 percent had one to six drinks per week, and 18.2 percent had seven or more drinks per week. In this study alcohol consumption was not statistically related to the presence of sores. However, the severity of pressure sores of participants who consumed seven or more drinks per week was higher (18.4%) than those who did not drink (13.5%). While the actual consumption of alcohol per se may not be problematic, the abuse or overuse of alcohol may result in behaviors not consistent with pressure sore prevention activities (i.e., decreased frequency of weight shifts, sitting on non-therapeutic surfaces).



Nutrition

Adequate amounts of protein, zinc and iron are necessary for the healing of pressure sores and are thought to have a preventive effect

on sore formation. The dietary intake of these participants was less than optimum. While the average caloric intake of the participants exceeded the recommended amount for individuals with spinal cord injury, the amounts of specific nutrients in the diet was lacking. Specifically, only 51.7 percent of participants consumed an adequate amount of protein; only 84.9 percent of the men and 23.1 percent of the women consumed an adequate amount of iron; only 48.2 percent of the men and 16.7 percent of the women consumed an adequate amount of zinc; and only 32.0 percent of the men and none of the women consumed an adequate amount of fluids!



Smoke Detector

Persons with impaired mobility need extra time and perhaps assistance to exit their home in time of fire. To ensure that all persons are warned of possible fires, it is recommended that every home have at least one operating smoke detector. Two-thirds of the participants (67.7%) had a working smoke detector in their home. Another 9.2 percent had a smoke detector installed but it was not in working condition. Almost one-fourth (23.1%) did not have a smoke detector in their home.



Water Temperature

Elevated hot water temperature is a burn risk factor for persons with impaired sensation. Tap water temperature should be no higher than 125° Fahrenheit. The mean hot water temperature measured at the kitchen sink in the participants' home was 121°. Although 81.4 percent were below 125°, 18.6 percent of participants were at risk for burns due to elevated hot water temperature.

Continued on page 6 - See CAPPS, Part II

Home = How You Live

By Bernie Quell, ASCC Intake Coordinator

Thinking of making changes to your home to increase your functional independence? It is important to analyze the potential result that you want the changes to bring about. No matter whether you own or rent, home equals how you live.

How functional is your home environment? Your home provides you the opportunity to use a certain amount of space. How much of your present living space are you able to access? Do you feel limited within the environment you call home? How welcome do you feel in your own home? Do you want your home to be more functional for your personal needs?

If the changes you are considering are part of your need to be more functional, more independent and more involved with your local community, then ask yourself the following kinds of questions:

- Would new equipment make a positive change?
- Can my functional needs be solved with equipment? If so, what kind?
- Can personal services solve my functional needs? (e.g., do I need someone to clean my

CAPPS, Part II

Continued from page 5

So, how do you think you would fare if you were a participant in this study and someone assessed your home and lifestyle? Are you doing every thing you could do to prevent pressure sores? Are you eating as healthy as you could? Are you getting enough fluids, especially during the Arkansas summer? Got a working smoke detector with batteries? Are you ready to make a change in your life/lifestyle? We hope so. There is always room for improvement and you deserve the best. Good luck!

house regularly or to shop for me?)

- What modifications to the home environment would promote the personal functioning of all who live here?

Making modifications to the home environment is no easy task. Having the financial resources is the biggest hurdle for many individuals. Time is another issue. You may need a quick fix to solve the immediate problem. However, if you explore the issue from a comprehensive manner, you are more likely to design a plan that promotes the financial and functional equity of your home. There are far too many good examples of bad modifications. A modification is an investment of your time, money and skill. A positive change requires the skill to coordinate and

direct the work, the necessary tools and materials and plans that direct the finished product. You want the result to be something you can be proud of, and be able to use.

If you are making changes that cost real dollars, you will want to think about the return on your investment. How much functional gain will you earn for the household members? If you, or other family members can be more independent because of the change, you will likely be getting a good rate of return on your investment. Investing in your home is as much an emotional issue as it is a financial one. You are worth the investment.

ASCC has information available on home modifications. Talk with your Case Manager about the changes that are right for you.

Regional Loan Closets Established



The Commission has established nine regional loan closets throughout the state. These new loan closets will store a variety of supplies and equipment typically needed by ASCC clients (*as pictured above*). This new system should result in greater accessibility to equipment at reduced cost. ASCC Case Managers coordinate all equipment loans.

Hope Miniconference

Joe McNiel of Hope (*right*) presented a session on personal conditioning for persons with spinal cord injuries at our mini-conference, *Spinal Cord Injury: An Update*, held at University of Arkansas Community College at Hope on July 27.

Nearly 50 individuals attended to hear Joe and other speakers discuss various topics including: aging with spinal cord injury, wheelchair selection, return to work and options for improving bowel and bladder function.



Disabled Sportsman Association 2001-02 Hunting Schedule



The Arkansas Disabled Sportsman Association has scheduled many events for this hunting season. Some of the hunts are in conjunction with the U.S. Army Corps of Engineers, International Paper, U.S. Fish and Wildlife Service, Arkansas Game and Fish Commission and individual landowners. Some of these hunts will require an application. If you have any questions or would like more information on any of the hunts listed below, please contact Toney LeQuieu at **870-933-5254**.

<u>Date</u>	<u>Type</u>	<u>Weapon</u>	<u>Location</u>
9/29 - 9/30	Squirrel	Shot Gun	Des Arc
10/20 - 10/21	Deer	Black Powder	Arkadelphia
10/26 - 10/28	Deer	Black Powder	Mountain Home
10/26 - 10/28	Deer	Black Powder	Arkadelphia
11/3 - 11/4	Deer	Black Powder	Clarksville
11/10 - 11/11	Deer	Modern Gun	Des Arc
11/17 - 11/18	Deer	Modern Gun	Des Arc
11/27 - 11/29	Duck	Shot Gun	Gillett
11/30 - 12/2	Deer	Black Powder	SE Arkansas
12/3	Deer	Black Powder	Heber Springs
12/7 12/8	Deer	Black Powder	Cooks Lake
2/9 - 2/10	Squirrel	Shot Gun	Des Arc
Season	Duck	Shot Gun	Waldenburg

New Videos and Books in the Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at **501-296-1792** or **1-800-459-1517**.

House for All Children (*video*) introduces six families who are raising children with a wide range of disabilities. They describe the modifications they made to create safe, accessible and supportive homes for their children.

The Healing Family (*book*) discusses using positive thinking

and mental imagery and cooperating with medical treatment in order to live a richer life. It helps each family member find their role in making a disabled family member healthier.

The Hidden Minority (*book*) focuses on the rights of the disabled. It teaches disabled persons how to become their own best advocate.

Life on Wheels (*book*) is an informative resource for every active wheelchair user. It discusses medical issues, day-to-day living issues, and psychological and social issues that relate to the wheelchair bound person.

The Pursuit of Hope (*book*) is written primarily for persons with MS who need a positive point of view. It demonstrates the hazards and the hope of multiple sclerosis.

We now have available a listing of accessible campsites around Arkansas. This list was provided through the Arkansas Game and Fish Commission. Please call the Resource Center to request a copy.



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